Youth and HIV/AIDS 2000:

A New American Agenda

OFFICE OF NATIONAL AIDS POLICY • THE WHITE HOUSE

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Table of Contents

1. AIDS is not over. Scientists believe that there have been 40,000 new HIV infections in the United States every year for the last several years, and that half of those being infected are young people between the ages of 13 and 24.

2. Most young people who are already HIV-infected don't know it.

3. The vast majority of HIV-infected youth do not receive adequate medical care.

4. For many young people infected with HIV, new medical treatments could lead to long, productive lives. To make this a reality, they need youth-friendly access to HIV counseling and testing, medical care (including mental health care), and other support services.

5. The best treatments fall far short of a cure and we have no vaccine. Behavior change is still the key to preventing HIV and protecting America's youth.

6. Prevention science has identified programs that can reduce risk behavior, but these programs are not offered in most schools and communities. Some of the proven programs were designed for small group or classroom use. With an emphasis on communication, negotiation and refusal skills, they state clearly that abstinence is important, and also provide information about condoms and other contraceptives. Other effective programs offer individualized counseling to high-risk youth, or use outreach workers to deliver prevention messages. A final group of programs mentor young people in activities that make the future seem brighter and staying safe seem worthwhile.

7. We still need answers to major questions about preventing and treating HIV and AIDS in young people. For example, we need to know how medical treatments for HIV affect a person who is still developing physically.

8. All young people need the tools to protect themselves from AIDS. The youth at highest risk of HIV infection need additional help. They are confronted with poverty, racism, sexism and homophobia. Many are out of school, lack access to health care, and are exploited by adults. Youth at highest risk urgently need school and community-based prevention programs that address all the daunting challenges they face.

9. Important parts of a comprehensive prevention/care system are now in place. There is more to learn, but we know enough now to tie key parts of the system together and extend it to cover all of our youth. This will take more resources, and more strategic use of existing resources. Working together, we can provide proper care to youth with HIV and AIDS, and we can turn the tide against new HIV infections in young people.

"It's nasty to talk about it. But if we mess up, we could get HIV. When are they going to start talking to us? We shouldn't have to do this alone."

17 year old Latina girl, California

A Message from the Director

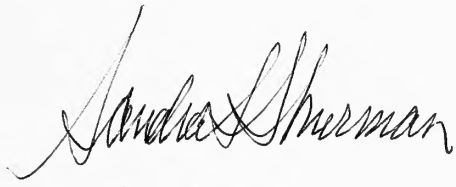
September, 2000

Alarmed at the threat HIV posed to America's young people, the Office of National AIDS Policy (ONAP) issued a wake-up call to the nation in a 1996 report, *Youth and HIV/AIDS: An American Agenda.* Americans under age 25 were becoming infected with HIV at the rate of two per hour, and the report named them a "generation at risk." Today, we report again on the status of the epidemic among young people, acknowledging progress made and calling for a reinvigorated national response to the problem.

The past four years have brought major advances and many young people have benefited from this success. New medical treatments have dramatically reduced AIDS death rates. We have also learned important lessons about preventing risk behavior and about providing youth-friendly services to the young people who are already HIV-infected. We now have strategies for bringing young people into scientific studies and for getting science out to practitioners who can put it to work for young people.

This good news is a return on our national investment in AIDS, but the good news is only part of the story. It is deeply distressing that the number of young people becoming infected has remained constant year after year and that most HIV-infected American youth are not receiving adequate medical care. Hard work and commitment have produced many of the tools we need for a successful campaign against HIV and AIDS in young people. While this innovation continues, we must move from paper to practice by putting what we already know to work for all young Americans. The time to act is now.

With the release of this report: *Youth and HIV/AIDS 2000: A New American Agenda,* we urge government at all levels, the private sector, parents, schools, community based organizations, religious institutions, concerned individuals and young people themselves to join forces in a renewed commitment to fighting HIV and AIDS in our nation's youth. Young people are our most valuable resource — our best hope for the future. The lessons we learn along the way will serve the entire global community.



Sandra L. Thurman
Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

Findings

THE PROBLEM:

Our best estimate is that *young Americans between the ages of 13-24 are still contracting HIV at the rate of 2 per hour.*

The AIDS epidemic is not over, and young people in the U.S. are not immune.

- Half of all new HIV infections are thought to occur in young people under 25.
- More than 123,000[1] young adults in the United States have developed AIDS in their twenties. The delay between HIV infection and the onset of AIDS means that most of these young people were infected with HIV as teenagers.
- The total number of youth in the U.S. who have been infected with HIV is unknown, but public health officials believe that 20,000 people between 13 and 24 years of age are infected with HIV every year.

Millions of American youth are still engaging in sexual behaviors that put them at risk for HIV/AIDS.

- HIV infection is usually contracted sexually among young people.
- By 12th grade, 65% of American youth are sexually active, and one in five has had four or more sexual partners.
- Each year, three million adolescents contract sexually transmitted diseases (STDs). That's about one in four sexually experienced teens. Of the 12 million Americans with STDs, about two-thirds are young people under age 25. These statistics indicate that many adolescents are engaged in unprotected sex—behavior that places them at risk of HIV infection.

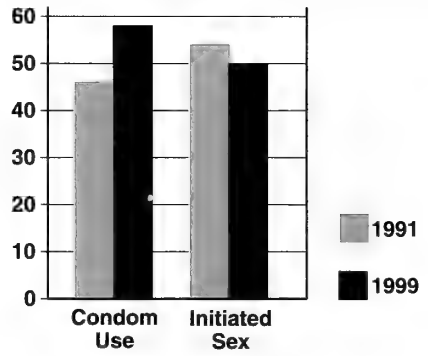
Fortunately, there has been a drop in sexual risk behaviors and an increase in condom use among sexually active high school students.

[1]All HIV and AIDS case statistics cited in this report are drawn from the most recent surveillance data from the Centers for Disease Control and Prevention (CDC); the reporting period extended through the end of 1999. This was also the most recent year that high school students' risk behavior was surveyed.

The percentage of high school students who say they have had sexual intercourse decreased from 54% in 1991 to 50% in 1999. The percentage of sexually active high school students who say they used a condom the last time they had sex increased from 46% to 58% during the same period (***see Figure 1***). Their accounts were confirmed when, in 1999, births to teenagers fell to their lowest rate in 60 years.

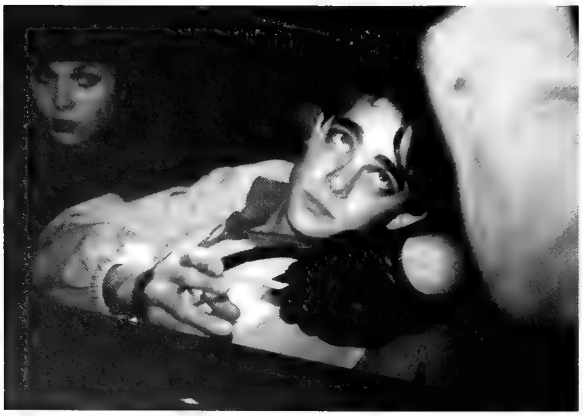
Figure 1

Percentages of U.S. high school students who reported having sex and using condoms, 1991 and 1999 Youth Risk Behavior Surveillance



Still, the number of young people having unprotected sex remains perilously high, and trends in risk behavior among some groups of youth are not as encouraging as those from regular high schools. Alternative high school youth, college students, sexual minority youth, and Native American youth have all reported higher rates of unprotected sex. Without expanded prevention efforts with these groups, their rates of HIV infection are likely to rise.

The abuse of alcohol and other substances also contributes to HIV risk in young people. It can impair judgment in sexual situations and can involve sharing injection equipment, a direct means of HIV exposure.



- Twenty-five per cent of U.S. high school students who have had sex said they were under the influence of alcohol or drugs (including marijuana and other illegal drugs, prescription drugs, and low-cost inhalants like gasoline, spray paint and glue) the last time they had sex.
- Binge drinking was recently reported by 31% of high school students. Among young people contacted at home, 38% of those 18-25 years old and almost 46% of those 21 years old reported binge drinking. The definition of binge drinking is having at least 5 drinks on the same occasion within the last month.

- An estimated 1.5 million Americans are current cocaine users, and about half of them are age 25 or younger. The use of crack has more than doubled among those 12-17 since 1991.
- About one in 50 high school juniors and seniors admited injecting illegal drugs.
- There is a normal tendency for young people to take risks. Those who engage in one risky behavior often engage in others. Young people who drink or use drugs are much more likely to have sex. On the other hand, those with the social skills to refuse unwanted or unprotected sex are also better able to refuse drugs.

Some young people are in even greater jeopardy.

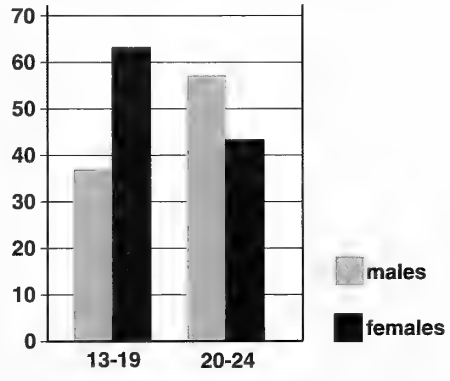
Any young person who engages in HIV risk behavior could become infected, but the epidemic has taken an especially heavy toll in certain groups of youth. Young women—particularly young women of color—and young men who have sex with men have been hit very hard by the epidemic.

Young women

- More females than males are now being diagnosed with HIV in the 13-19 year old age group (***see Figure 2***). In this group, 63% of the 828 HIV infections reported last year were among females. In the next oldest group, 20-24 year olds, women represent about 44% of the 2,386 HIV infections reported in 1999.
- In disadvantaged youth entering the Job Corps, young women from the South and Northeast had the highest HIV infection rates of all. Prevalences of up to 1 per 100 were found, with the highest rates in the District of Columbia, Florida, Louisiana, Maryland, South Carolina, Virginia and Connecticut.

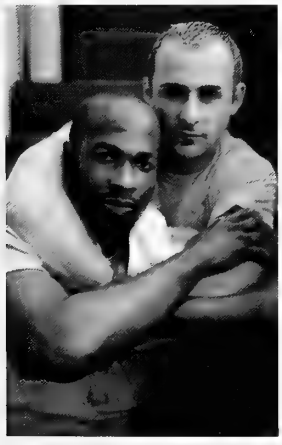
Figure 2

Percentages of HIV cases reported in 1999 among males and females in the 13-19 and 20-24 year old age groups[2]



[2] HIV data are reported by 33 states (not including California and New York) and the U.S. Virgin Islands.

Young men who have sex with men



- At least half of the HIV infections reported last year among young men aged 13-24 resulted from exposure to the virus through sex with other men.
- A recent seven-city survey of 3,492 men ages 15-22 who have sex with men found that, in the last six months, 41% had engaged in unprotected anal sex, an especially high-risk activity.
- Young urban men who have sex with men show alarming rates of HIV infection—just over 7%—with higher rates among African Americans, Latinos, and those of mixed race than among whites.

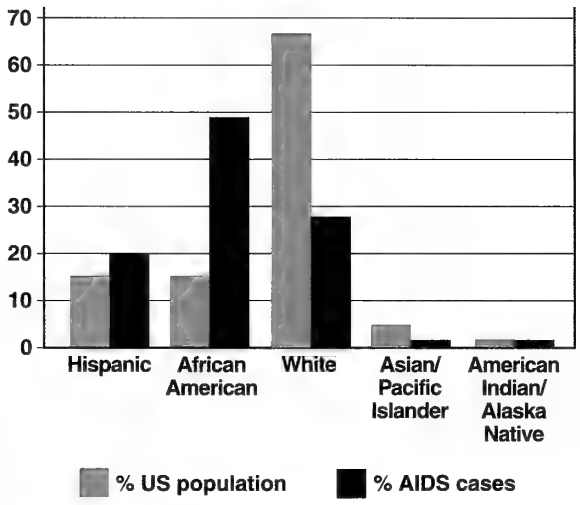
Minority youth

African American and Latino youth continue to be disproportionately affected by HIV and AIDS.

- African Americans and Hispanics each make up about 15% of U.S. teenagers. However, African Americans account for 49% of the 3,725 AIDS cases ever reported among those aged 13-19, and 67% of the 4,796 HIV infections reported to date in this age group. Hispanics represent 20% of AIDS cases among teens (***see Figure 3***).

Figure 3

Percentages of U.S. population and cumulative reported AIDS cases by Racial/Ethnic Groups among those 13-19 years of age



- There is a racial/ethnic disparity in the next oldest age group as well. Of the 25,904 cases of AIDS reported so far among those ages 20-24, people from racial or ethnic minority groups account for about 65%. Young women of color account for 78% of the AIDS cases among young women.

- For youth entering Jobs Corps, HIV infection rates were 7 times higher among African Americans than among their white counterparts.

Youth in high-risk situations

Youth who drop out of school, are sexually abused, run away from home, are incarcerated, are in other out-of-home residential placements, or are homeless remain at high risk for HIV and AIDS.

- About 4 million young people (12% of those ages 16-24 in the United States) are not enrolled in a high school program and have not completed high school. Compared with youth in school, out-of-school youth are significantly more likely to have had sex, to have had more than 4 sex partners, and to have failed to use a condom the last time they had sex.

- In 1998, there were more than 2.6 million arrests of youth under age 18. Over 100,000 juvenile offenders are in residential placement (e.g., jail, juvenile detention centers) on a typical day. Compared with other youth, youth in detention have engaged in much more HIV risk behavior, but they know less about HIV.
- Estimates of the number of homeless and runaway youth range from 730,000 to 1.3 million. Many of these young people use injection and other drugs and exchange sex for money, food, or shelter. One study of homeless youth in four cities found a median HIV infection rate of 2.3%. Some studies have reported rates above 10%.

Like adults in this country, America's young people may be growing complacent about AIDS.

"AIDS is kind of like school violence. You're like, 'it can't happen to me, it can't happen at our school,' and that's the attitude..."

Adolescent Health Clinic Client, Montefiore Hospital, New York City

Although most young people see AIDS as a major social problem and know the basics about how to protect themselves from HIV, they tend not to think that they are personally at risk.

- In a recent survey, 87% of young Americans said they do not believe that they are at risk for HIV infection. This impression can be tragically mistaken, and it can undercut the motivation to avoid sex or use condoms.
- Unrealistic expectations about the effects of medical treatments for HIV and lack of hope for a rewarding future can also contribute to a young person's complacency about HIV prevention.

Proven HIV prevention models have not been widely adopted.

Almost all states have policies that support HIV prevention in schools, but local communities generally make their own decisions about curricula. There is credible evidence that several prevention programs that are appropriate for classroom use can lower HIV risk behavior among young people (***see the box on Programs That Work, page 6***), but many school districts have chosen *not* to adopt these evidence-based programs.

There also continues to be a very dangerous dearth of prevention services for high-risk youth who don't attend school regularly, who drop out of school, who have been incarcerated or placed in some other out-of-home residential setting such as foster care, or who are homeless. Again, there are effective community-based models. Numerous programs are underway around the country, but the unmet need remains striking.

Programs that Work

The National Institutes of Health (NIH), CDC, and other Federal agencies fund well-designed evaluations of HIV prevention programs, and the results of many of these studies are published in the scientific literature. CDC identifies effective programs so that they can be drawn to the attention of prevention service providers.

To qualify as effective in one ongoing literature review, a program must be intended for school-aged youth, have a curriculum that is a complete set of procedures appropriate for classroom or other small group use, have an evaluation published in a peer-reviewed scientific journal, and show scientifically credible evidence of reducing sexual risk behavior without increasing sexual behavior. Five "Programs That Work" have been identified by this review to date; three target minority youth. Two were designed for both middle school and high school-aged youth, and three were developed for high school-aged youth only. All involve several hours of instruction and supervised activity. They not only teach facts about HIV and its prevention, but also help develop communication, negotiation, and refusal skills. They are interactive, offering opportunities for practicing interpersonal skills and for group discussion. CDC posts fact sheets about these programs on the web (http//www.cdc.gov/nccdphp/dash/rtc/index.htm). In the first year after a new program meets 'Programs that Work' criteria, there are usually two national trainings on its procedures. After that, the curriculum publisher and state education agencies sponsor additional trainings.

Another ongoing review, the HIV/AIDS Prevention Research Synthesis (PRS) Project, identifies programs that have worked to reduce sex or drug-related risk among either young people or adults. In addition to reviewing evaluations of programs suitable for small groups, PRS examines research on programs that used other means to deliver prevention messages such as peer and street outreach, individualized counseling, distribution of localized print materials, and multiple strategies in various combinations. Programs that qualify are described in the "Compendium of Effective Interventions to Reduce HIV" which is also available on the web (http//www.cdc.gov/hiv/projects/rep/compend.htm). Training in these program procedures will soon be offered at four regional training centers. Materials and scripts used in the effective programs are being packaged for easy replication by CDC and NIH.

School-based programs

- Youth at high risk of HIV infection are often still in school and eighty per cent of junior and senior high schools include HIV prevention as a topic in a required course. However, only 33% of the teachers who considered HIV a major topic in their courses discussed the correct use of condoms.
- In that survey, only 31% of teachers reported receiving training on HIV-prevention in the previous two years.
- The shortest of the small group-based prevention "programs that work" with adolescents is five one-hour sessions long. Almost 50% of teachers who teach about HIV reported spending only one or two class periods on the topic.
- In surveys conducted in high schools in Boston and the state of Vermont, 3%-5% of students reported same sex activity. There are effective prevention programs for gay youth, but few schools have made such programs available to students.
- There is limited Federal funding to support STD education in schools.

Community-based programs

- Young people between 13 and 24 constitute only 16% of the population at large. With an estimated 50% of new HIV infections, they are heavily over-represented in projected statistics. Nonetheless, only 25 of the 120 community planning groups charged with setting priorities for local use of Federal HIV prevention funds identified youth as a priority target audience.
- Organizations that provide support for gay youth exist in only 33 states and the District of Columbia; most of these groups provide services only in one or two major cities.
- Promising models are emerging for integrating HIV prevention into juvenile justice settings and other venues that serve youth in high-risk situations. Relevant technical assistance is available from several national non-governmental organizations, and many community-based organizations and health departments target this population. Still, most experts agree that there is a very large unmet need for community-based HIV prevention services for youth in high-risk situations.

More research on creative prevention models could identify effective new approaches.

"My parents bring it up because they know that they should, but they don't know what to say. So they're like, Do you have any questions? Anything you want to know? No? Well, it's good that we talked."

Teen focus group participant, Parent HIV education program, Ithaca, New York

- Programs that help parents communicate with their children about HIV may lower youth risk behavior. The first data on this kind of program outcome are only now being collected.
- Youth development programs *(**see A Shift in Approach: Positive Youth Develpoment**)* range from late-night sports teams to computer clubhouses. They are becoming increasingly widespread and they often bring to bear private sector resources that could make a big difference for at-risk youth. Unfortunately, few of these programs have been rigorously evaluated. The ones that are community-based have received less attention than the ones with activities in schools.

A Shift in Approach: Positive Youth Development

A successful transition to adulthood involves more than avoiding drugs, violence and risky sexual activity. Instead of focussing on problem behaviors, some new prevention programs are helping create circumstances that foster resilience. Called "youth development" programs, these approaches were the subject of a recent review sponsored by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the Department of Health and Human Services (DHHS). In the review, a program was considered effective if there was scientifically credible evidence that it increased positive behaviors like academic achievement and/or decreased risk behaviors.

The effective programs: (1) built competencies and self-efficacy (the belief that trying will result in success), (2) helped families and communities send consistent messages about standards for positive behavior, (3) expanded opportunities and recognition for youth who engage in positive behavior and activities, (4) provided structure and consistency in program activities, and (5) lasted at least 9 months. Two-thirds of the successful programs used the combined human resources of families, communities, and schools, thus increasing an adolescent's sources of contact with healthy adult role models.

The Seattle Social Development Project combined "Catch 'em Being Good" parent training with training for teachers in proactive classroom management, interactive teaching, and cooperative learning methods. When students were in 6th grade, they learned to resist peer influences to engage in problem behavior and to think of positive activities that would keep them out of trouble. Six years later, compared with similar students who did not participate in the program, fewer program students had had sex. Those who had started to have sex had had fewer sexual partners.

Another program, "Teen Outreach," was sponsored by a private-sector women's group. It got high-risk high school girls involved in volunteer work. The girls also received social competence training in classrooms. One year later, they were less likely than non-participants to have gotten pregnant, to have failed in school, or to have been suspended.

- There is a chronic lack of coordination of youth services and programs with related content (e.g., HIV prevention, pregnancy prevention, STD prevention, and drug prevention and treatment). This lack is evident within Federal agencies, between Federal agencies, and at the state and local levels. Research is needed to identify models of effective service coordination.

Treating other STDs and drug abuse reduces the risk of HIV infection, but youth face a shortage of both types of treatment.

- STD treatment reduces the risk of HIV infection by healing open sores or lesions, and an STD diagnosis constitutes a powerful "teachable moment" for HIV prevention. Nonetheless, STD screening and treatment services are underfunded. For example, in the country's most populated areas, chlamydia screening reaches only 20% of the young women in need.
- Dependency on illicit drugs or alcohol was reported by approximately 1.3 million people between 12-17 years of age who responded to a national household survey in 1999. In the same survey, responses from those ages 18-25 indicated that 3.4 million were drug or alcohol dependent.
- By contrast, only 296,000 of those in the 12-17 year age range and 561,000 of those 18-25 years old reported receiving substance abuse treatment. Many drug treatment facilities have waiting lists.

Most young people who are HIV-infected don't know it.

- Millions of young people who have engaged in high-risk behaviors do not know their HIV status. There are an estimated 250,000 Americans who unaware that they are HIV-infected, and many of them are young people.
- A person who is HIV-infected must know it in order to take advantage of promising new treatments for HIV. In a recent survey of young men who have sex with men, 249 were found to be HIV positive. Only 18% of them knew they were infected before the survey, and only 15% of them were receiving medical care.
- Research has shown that knowing one's positive HIV test results brings about significant reductions in risk behavior, avoiding transmission of the virus to others.

Young people who have had unprotected sex or who have shared needles should be encouraged to seek voluntary HIV counseling and testing. If the test result is positive, they should be linked to a comprehensive system of care. If the result is negative, they should receive HIV prevention counseling.

Young people face many barriers to HIV counseling and testing.

The prospect of getting a positive HIV test can be overwhelming. In addition, there are practical barriers to learning your HIV status if you are a young person in the United States.

- Many youth at risk of HIV infection have no doctor or other health care provider to turn to for advice.
- Young people may not know how or where to get an HIV test. Even if they know where to go, there are still logistical problems. For example, some counseling and testing facilities are open primarily during school hours, and some sites offer counseling in English only.

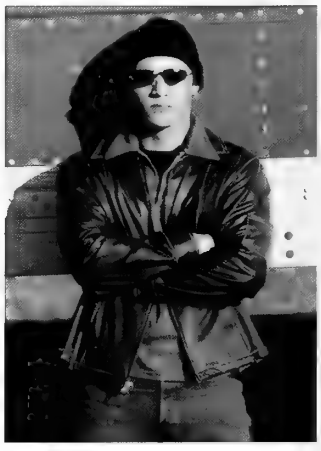
"I think some teens are afraid to get tested because they think their parents are going to find out."

Second Baptist Church Youth Group Member, Fairfax, Virginia

- Some young people are under the false impression that they are tested for HIV during routine medical exams (e.g., gynecological check-ups), and they assume that they would be notified if they tested positive.
- Parental consent is not required for HIV testing, but some teens avoid testing because of doubts about the confidentiality of their test results. These doubts are often warranted; some states allow parental notification of a positive test result at the physician's discretion, and one state requires parental notification.
- Reliable HIV tests that provide immediate results (so-called rapid tests) are not yet licensed and on the market. Young people who do manage to overcome initial barriers to HIV testing often fail to return for test results that take more than a week to become available.

HIV counseling and testing help a young person most when these services are tailored to his or her mental and emotional state, language, culture, and sexual orientation. There are too few youth-friendly testing sites. Special training can equip staff to work with young people in a supportive way that accommodates their unique needs.

HIV-infected youth are not receiving the health care they need to live as long and as productively as possible.



Because most young Americans with HIV infection don't know they are infected, they can't receive proper medical care, even when it is available. In fact, many young people find out they are infected only after they become seriously ill, too late to benefit from early treatment. Those that learn that they are HIV-positive may not have access to adequate care. Compared with children and older adults, young people are much less likely to have medical insurance. Those who are insured may not be covered for some key services such as mental health care. On top of that, many of those who are insured have trouble finding health care providers who are experienced with youth and who also know a lot about HIV. For young people who live in small, rural communities, it can be very hard to find appropriate services close to home and confidentiality concerns are often heightened.

- One study estimated that only 11% of youth living with HIV in the United States receive adequate medical care.
- Roughly one in three 18-24 year olds has neither public nor private health insurance, and the number of uninsured continues to climb each year.
- In 1997, low-income people aged 19-20 had the highest uninsured rate of all groups — 47.7%.
- The largest gaps in medical services for youth are in substance abuse and mental health services, both of which are central to the needs of many HIV-infected and at-risk youth.

Biomedical research has led to great strides in HIV/AIDS treatment, but much remains to be learned about the progression and treatment of the disease in adolescents.

- New treatments have produced dramatic reductions in the number of deaths from AIDS. Among those 15-24 years of age, the number of deaths in 1998 was 53% less than in 1996.
- Too few adolescents have participated in medical research to allow confidence that they will react to AIDS medications and dosages the same way adults do. Clinical research with HIV-infected youth is hampered by the small number of HIV-positive youth receiving care, and by the unique challenges of recruiting and retaining adolescent research participants.
- The systems for conducting medical research for HIV-positive youth are newer and less developed than those for children and adults. Young people also continue to make up a very small percentage of participants in clinical studies that are not youth-specific (e.g., vaccine trials). Young HIV-positive people are the best potential source of guidance in recruiting their peers and keeping them involved.

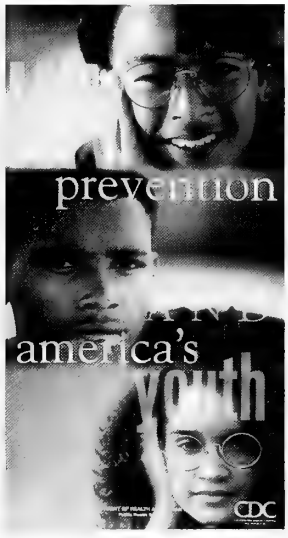
In many cases, the findings just described echo the findings about the status of American youth and HIV that were listed in the 1996 ONAP report (***see Attachment B***). The following section of this report describes the Federal response to these complex, persistent issues with an emphasis on action taken during the last four years. It is not possible to list here all of the activities carried out during this period by any Federal agency, but an attempt has been made to include the major ones.

THE RESPONSE:

Since the release of the 1996 ONAP report to the President, *Youth and HIV/AIDS: An American Agenda,* significant progress has been made. Prevention and care programs for young people have been strengthened, and research has generated important new medical treatments. However, many young people who are either infected with HIV already or at risk of HIV infection have not benefited from the advances of the last several years. Reaching all of our youth will take additional resources, coordinated effort, and the political will to support proven strategies.

PREVENTION RESPONSE:

The Federal government supports a wide range of programs to prevent HIV infection, most of which are administered by the CDC. Other Federal agencies also play key roles. Between FY 1996 and FY 2000, Federal funding for HIV prevention programs increased from $638 million to $1.057 billion.



Federal agencies and offices support state and local HIV prevention programs both financially and technically. For example, the DHHS Office of Minority Health (OMH) funds local prevention programs that use strategies ranging from teen theater to peer counseling to prevent HIV among minority youth. OMH also provides technical assistance in the development of organizational infrastructure. This assistance helps minority organizations and coalitions become stable, ongoing sources of prevention services. OMH also helps prevention service providers deliver messages in formats that are likely to be acceptable to minority youth and their families.

Spreading the Word about HIV

The National AIDS Hotline (1-800-342-2437) is a free source of answers to basic health questions. It also offers referrals for service and for more in-depth information. Between July 1999 and June 2000, the AIDS Hotline received approximately 143,580 calls from people ages 18-24, and 39,484 calls from people under age 18. A National STD Hotline received thousands more. In addition, the AIDS Hotline's "Classroom Calls" program reached more than 4,000 young people.

The National Prevention Information Network (NPIN) provides in-depth information about HIV/AIDS, STDs, and tuberculosis. Through a toll-free telephone line (1-800-458-5231) and a web site (http://www.cdcnpin.org), NPIN serves thousands of researchers, educators, health care professionals, parents, and young people each year. NPIN also links the public to other Federal information sources such as the Office of Minority Health Resource Center (www.omhrc.gov, 1-800-444-6472), the AIDS Treatments Information Service (ATIS) (1-800-HIV-0440), and the AIDS Clinical Trial Information Service (ACTIS) (1-800-TRIALS-A) maintained by the National Institutes of Health (NIH).

Monitoring the HIV/AIDS Epidemic

CDC monitors various aspects of the HIV/AIDS epidemic by age group on a continuous basis. A number of surveillance tools are used to track youth and adult risk behavior, HIV tests given at publicly funded sites, reported cases of HIV and AIDS, and AIDS-related deaths. These statistics are stripped of any information that could identify individuals and reported by states and local areas to CDC. CDC compiles the statistics, analyzes them, and makes them available to the public on the **worldwide web (www.cdc.gov)** and in libraries across the country.

In addition to ongoing surveillance, special studies are conducted by NIH and CDC when there is a need for additional information on particular risk groups. For example, the Young Men's Study gave HIV tests and interviews about risk behavior to thousands of young men who have sex with men in seven large U.S. cities, and then repeated these procedures several years later. This allowed scientists to gage trends in HIV-relevant knowledge, attitudes, and behavior and in HIV infection rates among members of this high-risk group.

Between FY1996 and FY2000, CDC funding for domestic HIV prevention increased from $584 million to $695 million. A large portion of this funding supports HIV and AIDS surveillance (***see sidebar on Monitoring the Epidemic***), efforts to ensure a safe blood supply, and laboratory research (e.g., on microbicides). This funding is also the major source of Federal financial support for community-based HIV prevention programs. Through cooperative agreements with health departments, CDC supports all 50 states, seven territories, the District of Columbia, Puerto Rico, and six high-incidence cities in conducting a variety of HIV prevention activities. They include voluntary HIV counseling and testing, health education and risk-reduction, public information, and community planning.

Community planning is a process that allows community volunteers and health department staff to set priorities for local HIV prevention activities funded through the cooperative agreements with CDC. During FY 1999, $268 million went to local areas through the cooperative agreements, and Community Planning Groups (CPGs) allocated about $56 million to local organizations that provide community-based prevention programs to youth.

The 1996 ONAP report recommended greater youth involvement in the CPGs. The National Association of State and Territorial AIDS Directors was funded by CDC to compile a case study of CPG experiences with youth involvement. Several other national organizations also have been funded to increase youth involvement.

CDC also awards funding directly to some local organizations —mainly those that provide prevention services to hard-hit racial and ethnic minorities. Eighty-four of these grantees serve youth, and many of them serve other age groups too.

In addition, CDC receives and distributes about $45 million per year for HIV prevention activities in secondary schools, post-secondary institutions, and settings that serve youth in high-risk situations. The funding goes to education agencies in states and large cities and to national non-governmental organizations. CDC strongly recommends that HIV prevention be undertaken in the context of coordinated school health programs; more than 180,000 teachers each year are trained in the administration of such programs. This funding also helps grantees implement sound school HIV prevention policies, develop and disseminate HIV prevention curricula, and evaluate these prevention activities. Grantees are directed to work with the most at-risk populations.

The CDC's "Research to Classroom" project identifies curricula that have good evidence of reducing sexual risk behaviors in either classroom or community settings. In the last four years, new curricula have met the stringent scientific criteria CDC uses to assess prevention program effectiveness.

At this point, most students are learning at least something about HIV in school:

- There was an increase in the percentage of high school students who said they were taught about HIV/AIDS in school between 1995 and 1997 (from 86% to 92%).
- Many schools have established notable HIV education programs, but not all students are offered evidence-based HIV education. Increased access to these effective programs was a major theme in the last ONAP report. Local political constraints, limited coordination between school officials and health departments, and level funding have stood in the way of making evidence-based HIV education more widely available in schools.

None of the curricula on the current list of programs that work uses an "abstinence-only" approach, but the 1996 welfare legislation made available a total of $250 million over five years to support programs that have "...as [their] exclusive purpose, teaching the social, psychological, and health gains to be realized by abstaining from sexual activity." As previously noted, the effective programs identified to date provide information about safer sex, condoms, and contraceptives, in addition to encouraging abstinence.

Programs that put an even greater emphasis on abstinence or delay of sexual debut deserve further scientific study, and such studies are being supported by NIH, ASPE, CDC, and many states. However, it is a matter of grave concern that there is such a large incentive to adopt unproven abstinence-only approaches.

As important as effective school-based HIV prevention education is, it must be part of a mix that includes community-based programs. They enable youth who have dropped out of school or who attend infrequently to receive life-saving information through trusted channels, in convenient places, and in formats that have been tailored to their diverse needs.

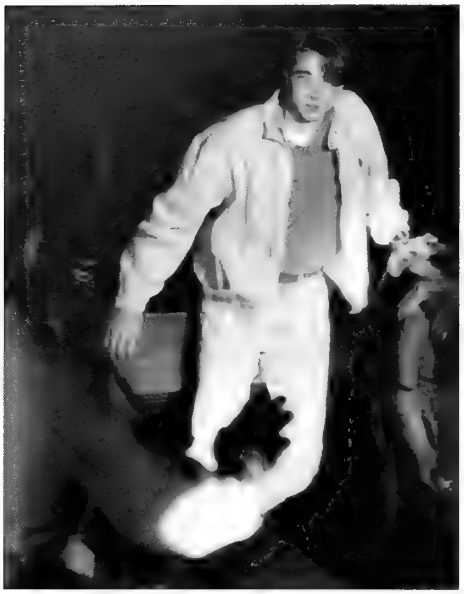
We do not know enough about the extent and range of community-based services for high-risk youth. Many of these services are sponsored by private sector entities or funded by block grants that do not require reports back to the government about how funds were used. However, there is widespread agreement among those who work with and study young people that many high-risk youth are not being served.

Community-based programs often respond to the reality that HIV risk behavior does not occur in a vacuum. Young people have other pressing concerns (e.g., poverty, lack of adult mentoring, sexual abuse, sexual identity issues and drug and alcohol dependency) that must be addressed if they are to avoid unsafe sex.

Substance Abuse Treatment and Prevention

For a number of reasons, drug and alcohol prevention and treatment are essential elements in the array of services needed to prevent HIV infection. Sharing equipment used to inject drugs is one of the leading sources of exposure to the HIV virus. Addiction can result in exchanging sex for drugs, a practice that carries major HIV risks. Again and again, youth who drink

heavily or use illegal drugs have been shown to engage in more risky sexual behavior than other young people. Even occasional substance abuse can impair judgment, making a young person more susceptible to pressure to engage in unwanted or unprotected sex. Fortunately, communication and refusal skills acquired in a substance abuse prevention program can help a young person resist sexual pressure as well as pressure to take drugs.



In FY2000, the Substance Abuse and Mental Health Services Administration (SAMHSA) awarded $1.6 billion to states through a Federal block grant program. This Federal funding represents about half of all public funding for substance abuse treatment and prevention programs. Funding for the block grant program has increased from just over $1.2 billion since the 1996 ONAP report.

States with 10 or more cases of AIDS per 100,000 residents are required to "set aside" 5% of the funds from their Substance Abuse Prevention and Treatment (SAPT) block grants for early intervention services related to HIV. These services must encourage voluntary HIV counseling and testing among substance abusers and their sex partners, and provide clinical services to those who are HIV-infected.

In addition, the states that use part of their SAPT block grants for treatment for injection drug users (IDUs) are required to provide outreach services to IDUs. Designed to encourage entry into treatment, the outreach services are often based on indigenous leader and health education models. Fifty-seven percent of the states that provide IDU treatment recently reported that their outreach services target high-risk youth as well as adult populations.

Finally, SAMSHA funds a High Risk Youth Program which is administered from the agency's national headquarters. This nationwide program develops and documents approaches to preventing drug and alcohol use among young people in high-risk environments, and disseminates the successful approaches. Examples include:

- Working with health department staff to make information and services relevant to HIV, STD, tuberculosis, and Hepatitis B and C accessible to adolescents in drug treatment in Tucson, Arizona.
- Placing emphasis on respect for heritage and tradition, relapse prevention, and breaking addictive cycles in chemical dependency and mental health treatment programs for hard-to-reach Native American youth in Alpine, California. Eligible youth are 12-18 years of age and come from families below the Federal poverty level. The program supports the individual, family and community in progress towards permanent recovery.
- Recruiting Newark, New Jersey adolescents at high risk of HIV and substance abuse for a teen theater company. Called "Teen-to-Teen," the troupe writes and performs one-act plays for teen audiences. The plays deal with HIV and substance abuse prevention, unplanned pregnancy, child abuse, weapons and violence, and other issues important to teens. The company members

also join adult facilitators in co-leading small group workshops on topics such as conflict negotiation and dealing with peer pressure. Ninety percent of the company members have continued their educations beyond high school.

- Using peer outreach workers to establish *and maintain* contact with homeless minority youth in Bridgeport, Connecticut who are involved with the criminal justice system, practicing survival sex, and abusing drugs. The outreach workers accompany clients to service appointments, finding those that miss appointments. Prevention case managers, substance abuse counselors and mental health workers all provide client-centered services out of the same facility.

In 1999, the Minority AIDS Initiative significantly increased SAMHSA's funding for substance abuse prevention and treatment services for youth of color. But despite these and other initiatives by government and the private sector, the shortfall of youth-targeted, community-based services remains acute. As the last ONAP report emphasized, we need more widespread sharing of information about programs that work, more financial support for HIV prevention and related prevention education, more support for substance abuse and STD treatment programs, widespread replication of existing models with evidence of effectiveness, and more good new HIV prevention ideas.

New intervention models

Over the last few years, there has been some Federal support for new types of HIV prevention programs. Promising new approaches include enhancing parent-teen communication, youth development and service learning programs, "safer schools" initiatives, multi-level interventions (e.g., programs that target students, their parents, and their teachers), and social marketing campaigns.

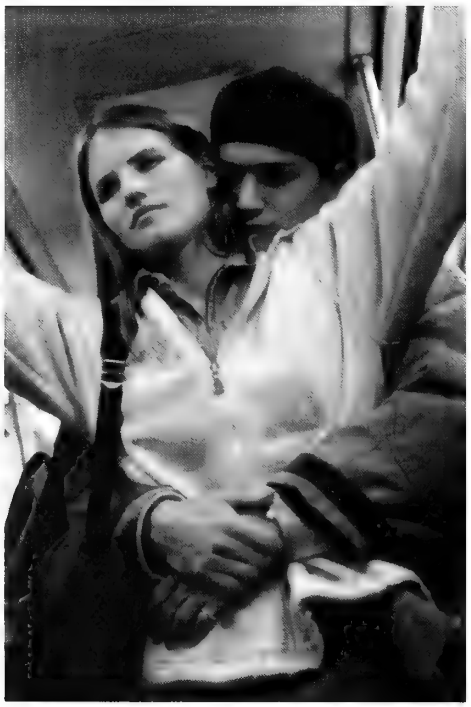
Social marketing—the use of media campaigns and other marketing strategies to influence behaviors and attitudes—has received a lot of attention because it has the potential to reach so many young people. For example:

- The National Institute on Drug Abuse distributed post cards containing science-based information on drug abuse and addiction in locations such as record stores, coffee shops, bars, movie theaters and gyms.
- CDC released radio and TV spots tailored for minority youth audiences to stations throughout the country as part of its Prevention Marketing Initiative (PMI). In 5 PMI demonstration cities, volunteer coalitions (including youth) planned and launched multi-channel youth-oriented social marketing campaigns that reached thousands. An eval-

uation at the Sacramento, California PMI site showed that, community-wide, a reduction in teen risk behavior was associated with exposure to the campaign.

- Six national organizations have been funded by CDC to mount HIV prevention communication campaigns targeting young people. For example, the National Council of Negro Women is conducting a national communication project focusing on young African American women.

In some of the newest social marketing work, campaigns are being designed to encourage high-risk individuals to get voluntary HIV counseling and testing, the first step on the road to adequate care.



- HIV-infected young people, most of whom are unaware that they are infected, are a key audience for targeted "Know Your Status" campaigns that CDC will soon launch.
- An emphasis on high-risk young people is part of National HIV Testing Day, a Federally-funded campaign organized by the National Association of People with AIDS. The campaign encourages youth who have engaged in risk behavior to learn their HIV status.
- With co-funding from Health Resources and Services Administration (HRSA) and private sources, the NIH Adolescent Medicine HIV/AIDS Research Network created Project ACCESS, a youth-oriented social marketing campaign to promote HIV counseling and testing. Using print, radio, and television ads, the project reaches young people with language and images that reflect youth culture. The project was pilot-tested in New York in 1997 and 1998. Project ACCESS is now expanding to Baltimore, the District of Columbia, Los Angeles, Miami, and Philadelphia with $1.2 million from the HHS Minority AIDS Initiative.

Since 1996, Federal agencies have taken several other important steps to expand HIV counseling and testing for high-risk youth. For example, CDC is developing guidelines to help HIV test counselors respond to the unique needs of adolescents and young adults. The Food and Drug Administration (FDA) and CDC are working together to speed the approval of reliable HIV tests that provide immediate results, eliminating the time delay that has resulted in a failure to return for results. CDC also offers a course on youth-centered, client-focused prevention counseling.

Such activities should help young people learn their HIV status so that they can enter care, but the Federal resources devoted to this effort are still meager compared to the number of youth at risk of HIV infection. As the following section on care and treatment makes clear, much more remains to be done to provide developmentally appropriate, culturally competent HIV counseling and testing to all the young people who have engaged in HIV risk behaviors.

CARE AND TREATMENT RESPONSE:

Early medical care and other supportive services are making it possible for some HIV-positive young people to live longer and to enjoy greater quality of life. Treating problems before they become serious may also reduce overall medical costs.

The Federal government provides care and support for young people living with HIV and AIDS through HIV-specific programs and health insurance coverage. Between 1996-1999, discretionary Federal spending on HIV-specific care and support programs increased from about $1.4 billion to $2.2 billion. In addition, each year almost one million 15-20 year olds receive Early Periodic Screening, Diagnosis and Treatment (EPSDT) exams through Medicaid. Finally, a new Federal initiative, the Children's Health Insurance Program, has made more adolescents eligible for health insurance coverage.

Despite this considerable investment, there are relatively few HIV-positive youth in care. In part, this is because many HIV-positive youth do not know that they are infected. Other barriers to health care access include remaining gaps in health insurance coverage, a shortage of health care providers with expertise in both HIV and adolescent medicine, and confidentiality concerns.

HIV Medical Care and Supportive Services

The Ryan White CARE Act (RWCA) is the largest discretionary Federal program dedicated to HIV care and treatment. RWCA is administered by HRSA. Across the country, this program supports a wide range of community-based services including primary and home health care, access to medications, case management, mental health services, dental care, nutritional services, and linkage to substance abuse treatment and housing assistance. As the number of people requiring care has increased, RWCA has grown from a $220.5 million program when it began in 1991 to a $1.6 billion program today. Youth are eligible for all RWCA programs, which are targeted to specific populations on the basis of local needs assessments. Approximately 7% of the 500,000 clients served in Titles I, II, and III of RWCA (provisions authorizing grants to high-incidence cities, to states and territories, and to primary healthcare systems and community-based organizations) are young people between 13 and 24 years of age.

In addition, Title IV of RWCA funds sites to reach out to children, youth, women, and families and to provide them with comprehensive care. There are Title IV grantees in 27 states, Puerto Rico and the District of Columbia. From 1995 to 1997 alone, the number of young people ages 13-24 served by Title IV increased by 225%. Title IV projects have been most successful at reaching young women, one of the fastest-growing groups of HIV-infected individuals in the country.

The research and development arm of RCWA is its Special Projects of National Significance [SPNS]. Young people were the sole focus of ten SPNS awards made in 1994. HRSA awarded $2.7 million in three-year grants to community-based organizations to develop and pilot-test innovative models of HIV care for adolescents and young adults. The projects explored various methods of outreach to HIV-positive youth and ways to increase early entry into primary care and support. In 1998, the findings of this first generation of adolescent demonstration projects were published. Some of the findings were that:

- HIV-positive adolescents in Indiana needed two case managers—one for social services and one for medical services. This level of service resulted in better physical health and in significant reductions in sexual and drug risk behaviors.

- Recreational activities helped retain youth in the care system. Staff in a program for substance-abusing youth in San Francisco had to become role models for having fun while clean and sober.
- Few at-risk girls in Birmingham, Alabama took advantage of SPNS services until the services were moved from clinic settings to community sites that were more familiar to the girls.
- At Children's Hospital in Los Angeles, treating SPNS youth in a primary health clinic for adolescents and young adults made it possible for them to sit in a waiting room without having anyone make assumptions about their HIV status.

One lesson from the first-generation SPNS projects was that youth infected through perinatal transmission have very different needs and concerns than those infected through sexual or drug use behaviors. Strategies for tailoring care for each of these two subgroups are among the topics being explored in three new adolescent SPNS projects that are still underway. To put SPNS findings into practice, HRSA established a $2 million Adolescent Initiative within Title IV. In addition, special training is offered to staff of programs funded under the other provisions of RWCA.

Youth projects are still eligible to apply for SPNS grants, but there is no longer a SPNS component dedicated to adolescents and young people. The Adolescent Initiative, which represents a very small fraction of Federal AIDS care dollars, is now the only ongoing RWCA program specifically for youth. It has made small grants to youth programs in just four cities (Boston, Chicago, New Orleans, and San Francisco) and Puerto Rico.

Overall, the number of programs that integrate primary care, specialized HIV medical treatment, mental health services, case management, and other supportive services into 1-stop shops has grown somewhat since the 1996 report, as has the number of youth enrolled. But there is a still a widespread need for replication of the service models that have succeeded in getting young people into life-saving care and keeping them there. Current treatments are extremely expensive and have demanding regimens. They can cause severe and sometimes disfiguring side effects, require intensive medical monitoring, and can stop working over time. All of these factors are of particular concern for youth, and services for young people should take these concerns into account. The demand for tailored care for young people will increase as treatments for HIV extend life and medical treatment becomes more complex.

Health Insurance

Medical care costs incurred by some HIV-infected youth are covered by Medicaid and other Federal programs that help low-income people cover general medical expenses. Since the 1996 report, significant progress has been made in extending health insurance to adolescents:

- Since it began in 1997, the State Children's Health Insurance Program (SCHIP) has helped insure over 2 million children and adolescents under the age of 19 whose family incomes are too high to qualify for Medicaid but too low to afford private health insurance.
- However, an estimated 41% of uninsured children and adolescents live in families with incomes that are too high to qualify for most state SCHIP programs.

Although Medicaid and SCHIP programs have helped many teens, health insurance for young adults is still sorely lacking. SCHIP and other public health insurance programs typically limit coverage to youth under age 19. This constitutes a major gap in coverage.

Housing

Beyond medical care, stable housing is one of the most important parts of the safety net for persons living with HIV and AIDS and their families. Youth who are homeless or who run away from home are at greater behavioral risk of HIV infection. Youth who are infected with HIV are more likely to be able to follow complex treatment regimens if they have a reliable address where they can be reached by care providers, a safe place to keep medications, refrigeration for drugs that require it, and other necessities that many of us take for granted.

- Federal funding for the Housing Opportunities for Persons with AIDS (HOPWA) program has increased every year since the last ONAP youth report, with an appropriation of $232 million for FY2000. Administered by the Department of Housing and Urban Development (HUD), HOPWA funds enable states and localities to work with nonprofit partners to plan, operate and evaluate housing for persons with HIV and AIDS.
- FY2000 funds provide housing assistance to 53,625 persons and related supportive services to an additional 23,700 persons with HIV and AIDS and their family members. Roughly 17% of persons receiving housing assistance are under the age of 17 and 18% are between the ages of 18 and 30.

HOPWA Special Projects of National Significance are able to provide services beyond housing to infected and at-risk youth. For example, the Center for Children and Families in New York City sponsors aggressive street outreach, specialized youth counseling, life skills training and other services at a drop-in center and a transitional housing program. The Center also provides technical support to over 100 local agencies and nonprofits that serve youth.

RESEARCH RESPONSE:

The Federal government supports AIDS research in a wide range of scientific areas. They include natural history, epidemiology, behavioral science, basic biomedical sciences, therapeutics and vaccine discovery, development and testing, health services, and social science. This portfolio resides in numerous Federal agencies. Within the Department of Health and Human Services, NIH, CDC, HRSA, and the Agency for Healthcare Research and Quality support most of the research; the Department of Veterans Affairs and the Department of Defense also contribute to the AIDS research effort. These agencies have internal research planning processes and bring in outside experts to help set research planning priorities. The agencies use scientific conferences and journals and other mechanisms to disseminate research findings to a variety of audiences (e.g., scientists, policy makers, local service providers, and the general public).

According to the Office on Management and Budget, Federal spending on AIDS research programs has grown from approximately $1.5 billion in FY 1996 to $2.1 billion in FY 2000. Basic biomedical research (e.g., the studies that led to the identification of the HIV virus and an understanding of how it destroys the immune system) represents about half of this research portfolio. In most cases, basic biomedical research is not specific to young people, but it is critical to the development and evaluation of preventive measures and medical treatments from which young people stand to benefit. Although we acknowledge the central importance of basic biomedical research, it will not be described here. Instead, this report will highlight some prevention and treatment research that focuses on young people directly.

The NIH supports the majority of Federally-sponsored AIDS research and, in FY2000, targeted approximately $60 million specifically to HIV/AIDS research with adolescents. Youth-focused HIV research is describing the extent of the HIV epidemic among young people, identifying effective HIV prevention approaches, revealing the effects of HIV disease in young people, and improving treatment regimens. In addition, NIH supports a large program of AIDS research with other groups (e.g., racial and ethnic minorities and pediatric populations) and on vaccine candidates and new treatments, and there are some young participants in this research. The agency also supports studies of adolescent sexual behavior that have direct implications for HIV research and practice.

Conducting the research necessary to further understanding, prevention, and treatment of HIV and AIDS in adolescents and young adults is an explicit priority for NIH and other Federal agencies. Funding for research on youth and AIDS has increased over the last four years, and we have learned a great deal, but we have not met all of the research challenges identified in the 1996 ONAP report (***see Attachment B***). Additional funding is needed to take advantage of research opportunities and to fill in knowledge gaps.

Prevention research

Over 20 adolescent-specific studies funded by NIH are currently examining factors that lead to HIV risk behaviors. In addition, more than two dozen NIH-funded studies are developing and evaluating social and behavioral interventions to reduce HIV infections among youth. For example:

- The National Institute of Mental Health (NIMH) is studying ways to delay initiation of sexual activity and promote consistent practice of HIV risk-reduction behaviors. These include studies of adolescents recruited from STD and family planning clinics, residential settings, and school- and community-based programs. Interventions that involve parents and other family members in HIV prevention are being developed and evaluated. NIMH currently emphasizes studies on homeless and runaway youth, youth of color, and gay youth.
- The National Institute on Drug Abuse (NIDA) is supporting a study on the relationship between substance use and HIV risk behaviors among

homeless adolescents. It is also funding studies on HIV risks among young women who are injection drug users or sexual partners of injection drug users, and risk reduction interventions for drug-abusing juveniles admitted to court-mandated treatment.

- The National Institute of Nursing Research (NINR) is supporting several studies on behavioral interventions for youth, especially youth of color. For example, a University of Washington study is examining disease prevention beliefs and behaviors related to HIV and STD infections among Pacific Islander adolescents. Results will be used to develop and test a culturally sensitive adolescent health and HIV prevention program.
- The National Institute of Child Health and Human Development (NICHD) is studying HIV-positive youth and is combining medical monitoring with a prevention intervention. Another set of NICHD projects is investigating risk behaviors in middle childhood that might lead to risky sexual behavior later on; researchers will follow the children until some are 24 years of age. NICHD is also investigating the ways in which attitudes and sexual behaviors are influenced by romantic relationships. Youth in foster homes and other high-risk situations are participants in additional studies.
- Targeting HIV-positive individuals with the goal of helping them avoid transmitting the virus is an increasingly important focus of prevention research. For example, NIDA is supporting a study that is looking for ways to reduce substance use and risk behaviors, increase health care utilization, and enhance quality of life for substance-abusing youth living with HIV.

Several institutes at NIH co-support the NIAID-sponsored HIV Prevention Trials Network. It conducts domestic and international research on promising biomedical and behavioral strategies for preventing HIV transmission among adult, pediatric and adolescent populations. Among the types of interventions studied in this network are behavioral interventions, vaccines, and physical and chemical barriers (e.g., microbicides). Additional studies of these types of interventions are supported through NIH-sponsored programs elsewhere in the agency. The successful development of these HIV prevention tools will be invaluable to young people.

NIH advisory groups have determined that more research is needed to address HIV prevention-relevant scientific questions such as:

- What influences do family, social and sexual networks have on youth risk behaviors?
- There are different approaches to HIV prevention for young people, including STD treatment, promotion of barrier methods such as condoms, and communication and refusal skills training. Promotion of microbicides will be added to the list when these products become available. How should these approaches be combined?
- What are the essential ingredients in successful prevention strategies for youth?
- How should "essential ingredient" information be communicated to service providers who are tailoring standard prevention programs for particular populations of young people?

CDC and SAMHSA also conduct HIV/AIDS prevention research. Among their current projects targeting youth are:

- Project SHIELD, a community-focused program that is developing and evaluating ways to reduce high-risk behaviors [SAMHSA].
- The Community Intervention Trial for Youth (CITY), which is developing and evaluating a comprehensive, community-level approach to encourage young men who have sex with men to reduce HIV risk behaviors. Young men of color are the primary target audience [CDC].
- Project START (STD and AIDS Reduction Trial), which is developing and evaluating innovative methods to prevent HIV and STD infection and transmission among young men in prison who are about to return to their communities [CDC].
- Teen pregnancy prevention coalitions in four cities have been funded to develop and test strategies for integrating HIV, STD and pregnancy prevention messages for minority youth [CDC].

Treatment research

NIH funds the majority of the research relevant to treatment for HIV and AIDS. The agency supports several research networks that conduct HIV/AIDS treatment research involving young participants, including the Pediatric AIDS Clinical Trials Group (PACTG), the Adult AIDS Clinical Trials Group (AACTG), the Community Programs for Clinical Research on AIDS (CPCRA), and the Adolescent Medicine HIV/AIDS Research Network (AMHARN). These networks evaluate antiretroviral treatments, medications for HIV-related opportunistic infections and malignancies, and medication regimens.

All the networks have begun to address the issues of simplifying treatment regimens for adolescents and recruiting and retaining youth in clinical trials. Recruiting young people into clinical trials remains difficult, and the concerns that young people have about participation may not be sufficiently understood.

Institutional review boards (IRBs) are standing committees at universities, hospitals, and other institutions that conduct research. IRBs examine research proposals to ensure that issues such as participant safety, confidentiality, and informed consent have been adequately addressed. IRBs must follow Federal regulations (promulgated by NIH) and state and local laws that protect minors as a special population. However, the potential value of information about young people should also be heavily weighted in IRB deliberations.

In 1994, the AMHARN was established by NIH to create an infrastructure for AIDS research specifically targeting adolescents ages 13 to 19. AMHARN's objectives are to: characterize the natural history of HIV in adolescents; study basic science questions about the susceptibility, infectivity, and transmissibility of HIV in adolescents; produce clinical management guidelines for adolescent HIV infection; and provide youth access to clinical trials. Two major Network initiatives are Project REACH and Project TREAT.

- Project REACH is an observational study of the biomedical, psychosocial, and behavioral aspects of HIV infection in adolescents. The project has enrolled approximately 350 HIV-positive youth and 180 HIV-negative high-risk youth at 15 clinical sites across the country. REACH has already yielded much of what is known about adolescent-specific responses to HIV infection.
- Project TREAT is a new effort to help adolescents participate effectively in complex treatment regimens. Project TREAT is developing, evaluating, and distributing a multi-faceted program intended to enhance treatment adherence. The project has produced a monograph on adherence support for clinicians treating HIV-positive adolescents.

HRSA (see the description of SPNS in the section on HIV Medical Care and Supportive Services) and CDC also conduct treatment-relevant research. Two large ongoing studies at CDC focus on children who were infected perinatally and are now adolescents. A new CDC study of HIV-infected adolescents will examine the continuity of care provided by HIV specialists, adherence to medical regimens, and strategies for preventing further HIV transmission.

The HIV/AIDS epidemic among our nation's youth demands increased scientific attention and a more efficient two-way information pipeline between scientists and those on the front lines of the battle against AIDS. Collaborative ground has been broken. Scientists and service providers are research partners in many studies around the country, and some mechanisms for dissemination of scientific information are in place. However, optimal information exchange will require new strategies for collaboration among Federal agencies and between researchers and practitioners.

Recommendations

Many of the specific Federal action steps that were recommended in the first ONAP report to the president on HIV and AIDS in America's youth (***see Attachment B***) have been taken over the last four years. This response required a serious commitment and is commendable.

However, two tragic realities have not changed. Some 20,000 young people are still becoming infected every year, and most of them are not receiving the medical care they need. The programs that provide HIV prevention, care and support services to youth must be broader in vision, larger in scope, and better coordinated. As pointed out by some of the recommendations that follow, there is certainly more to learn, but we know enough now to make a real difference if we work together.

The specific recommendations listed on the following pages begin to outline a plan of action. *These recommendations should be expanded into a three-year, comprehensive national plan that addresses the full range of issues pertaining to HIV/AIDS in youth, with special emphasis on the needs of young people who are at highest risk of HIV infection.* The national plan should identify gaps in our current response, and it should be updated on a regular basis. The President should designate a high-level point person to make sure that a National Youth HIV/AIDS Prevention Plan is developed, implemented, and kept up to date.

The Institute of Medicine (IOM) is conducting a comprehensive review of current HIV prevention efforts in the United States. Based on this review, the IOM has been charged with proposing a visionary framework for future national HIV prevention strategy. The IOM's final report, due in September, 2000, along with agency-specific plans that are in place or in progress, should be used to help inform a National Youth HIV/AIDS Plan that addresses prevention, research and care issues.

An effective plan will:

- be developed in consultation with all Federal agencies and offices responding to AIDS, as well as with young people, service providers, researchers, and advocates;
- create or reinforce strong linkages among Federal health and social service programs, such as STD, substance abuse, family planning, youth development programs; and
- provide a basis for future allocation of HIV prevention resources among and within Federal agencies.

PREVENTION RECOMMENDATIONS:

The Federal government should ensure that adequate resources are targeted to youth-focused HIV prevention, particularly prevention that targets youth at highest risk for HIV infection.

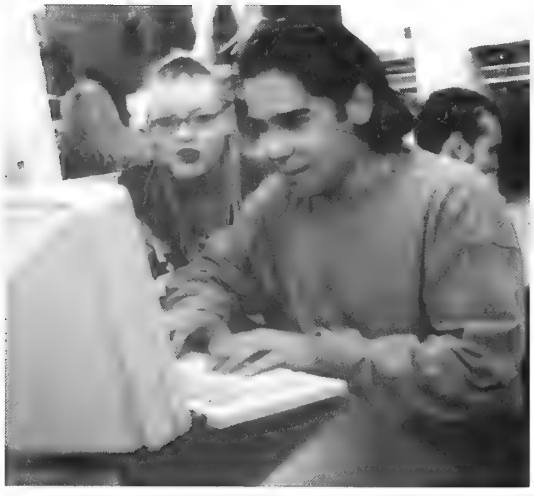
Although young people account for half of new HIV infections, less than a quarter of all HIV prevention program funding is directed towards this age group. Funding for in-school and out-of-school prevention programs that target high-risk youth is insufficient to halt the spread of HIV among young people in America.

- A substantial amount of new funding should be allocated for implementing the strategies identified in a National Youth HIV Prevention Plan.
- Federal agencies should use existing resources to expand youth-specific initiatives.
- All Federal funding for HIV prevention among young people should more equitably address the needs of youth at highest risk for HIV infection. They include youth of color, homeless and runaway youth, youth in other high-risk circumstances, youth who engage in substance abuse, and sexual minority youth.

High-quality HIV prevention programs should reach more youth in schools.

HIV prevention education has an optimal context—coordinated school health programs that speak to the full range of health issues affecting youth. These are issues such as nutrition, exercise, family planning, HIV and other STDs, injuries, and the use of tobacco and other substances.

Where there is scientific evidence that a unit on any of these issues is effective in promoting healthy behavior, use of that unit should be encouraged. Where there are no evidence-based units, development and evaluation of relevant curricula should be supported. Tools for education about other STDs should be developed further and made widely available. The HIV prevention component should definitely be evidence-based.

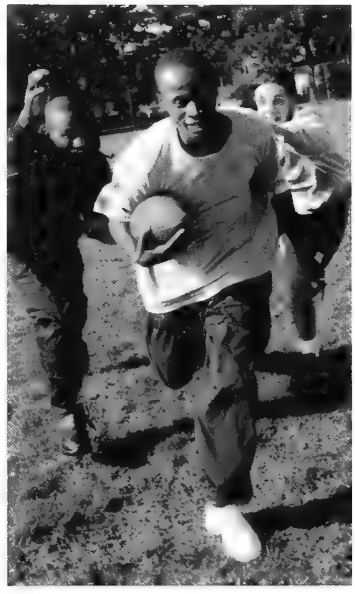


- CDC should do more to support and promote coordinated health education and evidence-based HIV prevention programs in the nation's 15,000 school districts.
- Schools and other prevention service providers should adhere to best practices as identified by prevention science, and those receiving new funding should be held strictly accountable for such adherence. A relatively large amount of Federal funding is currently dedicated to untested, abstinence-only programs. Priority for future funding increases should be given to programs with demonstrated effectiveness in decreasing behavioral risk of infection with HIV and other STDs, and of unintended pregnancy.

- Schools should increase and enhance the prevention services they provide to high-risk youth, consistent with priorities set by local community planning groups.

Community-based HIV prevention services for young people should be widely available, coordinated with other services, and user-friendly.

- Condoms should be made readily accessible to sexually active youth, and advertised in media that reach this target audience.
- CPGs should take additional steps to recruit and retain young people.
- CDC should expand training and support for collaboration among community planning groups, state and local education agencies, and other youth-serving organizations at the state and local levels. In addition, the National Youth HIV/AIDS Plan should include specific steps to improve coordination of youth prevention activities at the Federal level, both within CDC and across Federal agencies.



- The multiple systems and services that touch the lives of young people should integrate science-based HIV prevention into their ongoing activities. After-school programs, prevention programs that focus on issues other than HIV, church programs, programs for youth in the juvenile justice system, and one-on-one encounters with general practice healthcare providers are examples of resource-conserving opportunities for HIV prevention.
- As parts of a multi-pronged prevention strategy, STD education, screening and treatment, and drug abuse treatment should be supported at levels that make these services available to all young people who need them. Medicaid managed care contracts are one of the avenues that should be explored for expanding the availability of these services to young people who are eligible for Medicaid.

The Federal government should develop and implement an initiative to promote routine, voluntary HIV counseling and testing for at-risk youth.

The Federal government should mount an aggressive, multi-faceted campaign to promote voluntary HIV counseling and testing to youth who have engaged in HIV risk behaviors. The campaign should be at the scale of the remarkably successful public health effort to reduce HIV transmission from mother to child. The counseling and testing initiative should be a component of the National Youth HIV/AIDS Plan. It should build upon existing Federal initiatives to prevent HIV infection and promote HIV counseling and testing among at-risk populations.

Significant new resources will be necessary to fund this initiative. Its goals should be increasing the number of at-risk youth who seek HIV counseling and testing, increasing the number of HIV-positive youth who are diagnosed and linked to comprehensive care, and providing high-quality prevention services to at-risk youth whose test results are negative. As outcomes of this initiative:

- voluntary HIV counseling and testing should become a routine component of adolescent health care. For example, school health personnel should inquire about HIV risk behavior in the course of medical exams (e.g., those often required for playing sports) and offer HIV counseling and testing to youth who have engaged in risk behavior.
- HIV counseling and testing sites funded by CDC and HRSA should offer convenient, youth-friendly services to all youth at risk. The services should be designed to reflect the developmental and emotional needs, language and culture of young people.
- HIV testing sites and programs should have strong linkages to youth-friendly care and treatment facilities; and
- social marketing campaigns and other strategies should be used to encourage all at-risk youth to seek HIV counseling and testing.

The Federal government should encourage public/ private partnerships that address the full range of needs of high-risk youth.

High-risk youth need a variety of supportive services and continued contact over time with caring, knowledgeable service providers. Providing this level of support demands substantial resources, but there is no more worthwhile investment. Meeting the needs of our high-risk youth will take realism, creativity, and persistent hard work on the parts of families, communities, the private sector and government at all levels. Young people, parents, and other adults all have roles to play, but the Federal government must provide leadership and support for a coordinated effort.

- The report on adolescents in high-risk settings released by the National Research Council of the National Academy of Sciences should help guide the National Youth HIV/AIDS Plan.
- The President's point person on youth and HIV should identify categorical and other restrictions on Federal support for youth development programs (e.g., mentored volunteering) with evidence of lowering HIV risk behavior. Recommendations should then be made about when and how to remove barriers to public/private partnerships interested in resiliency-building approaches to meeting the needs of high-risk youth.
- There should be additional Federal support for the development and scientific evaluation of cooperative models of service that combine resources from the public and private sectors.

Increased support from the Federal government is needed for the development and dissemination of promising models of HIV prevention programs for youth.

- HHS agencies should redouble their current efforts to derive best practices from prevention science and local program experience, to disseminate this information to school boards, community planning groups, corporations, foundations and other decision makers, and to advocate for the adoption of effective HIV prevention models.
- The Federal government should find additional ways to help researchers and community-based HIV prevention service providers share information, and to help them work together.

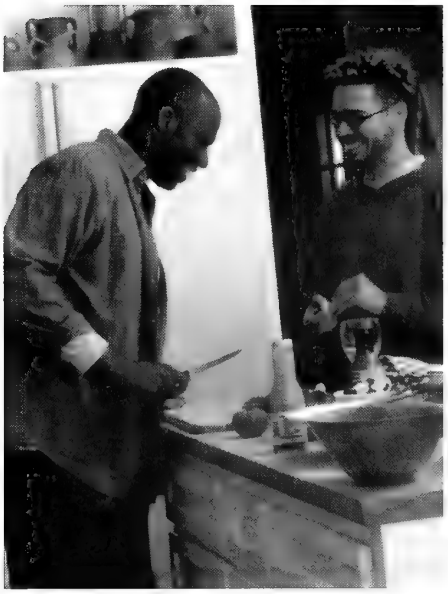
CARE AND TREATMENT RECOMMENDATIONS

The Federal government should ensure that all HIV-infected youth have access to comprehensive, community-based health care and supportive services that address their medical and psychosocial needs.

- Under current policy, people become eligible for Medicaid when they receive an AIDS diagnosis. Congress should act to expand this eligibility to cover all low-income people living with HIV. This is particularly important for HIV-positive young adults over age 18 because they do not qualify for the SCHIP program.
- The Federal government and States should expand efforts to enroll youth who are currently eligible for SCHIP and Medicaid into these programs.
- The Federal government should find new avenues to provide health care coverage for uninsured adolescents and young adults who exceed current limits on age or income eligibility for Medicaid and SCHIP.

The Administration should build on the Ryan White CARE Act to deliver care to youth affected by HIV and AIDS. As it stands now, only a small percentage of Federal AIDS CARE Act resources target youth.

- Within Title I and Title II of the Ryan White CARE Act, funds should be set aside for youth just as they are currently set aside for other special populations. Funding of services for youth should, at a minimum, be proportional to the percentage of cases of HIV/AIDS that young people represent.
- Increased funding for the Ryan White CARE Act Title IV Adolescent Initiative could provide resources to communities that have significant populations of HIV-positive youth but are not currently funded under the initiative.
- New funds could support evaluation and quality assurance for Title IV Adolescent Initiative programs. Support for building permanent service links with substance abuse, mental health, family planning, and adolescent primary care programs should also be provided.



For youth living with HIV/AIDS, housing is an essential component of comprehensive care, but many at-risk and infected young people lack stable housing. Additional assistance will help provide housing, access to care and supportive services, and a stable base that helps make it possible to maintain adherence to often difficult medical and other therapeutic regimens.

- Funding for HOPWA should be expanded to serve the growing number of low-income persons who are living with HIV and AIDS and who need housing assistance, including families and youth.
- HUD should encourage state and local governments to undertake coordinated planning and service delivery in the areas of housing, health-care, mental health, substance abuse, skills training and other services that are relevant to the needs of at-risk and HIV-infected youth.

The Federal government should improve the quality of services for HIV-infected youth.

- The Federal government should provide additional funding for training and technical assistance programs to help HIV treatment and care providers respond to the unique developmental and psychosocial needs of young people living with HIV and AIDS.
- More health care providers could be recruited and trained specifically to treat young people with HIV. One possible recruitment approach would be to create incentives such as scholarships and loan repayment programs within the National Health Service Corps for health professionals who commit to working with adolescent HIV care programs.
- To respond to emerging issues in adolescent HIV care, HRSA could continue to fund a significant number of youth-focused projects within SPNS.

RESEARCH RECOMMENDATIONS

The Federal Government should ensure that its research agenda for HIV/AIDS includes a component targeted to youth.

Research related to HIV and youth is being conducted by a number of Federal agencies, and regular review of the entire portfolio could be valuable in identifying research gaps and setting priorities. The planning procedure instituted by the Office of AIDS Research (OAR) at NIH over the last several years is a possible model for this review.

- HHS should ensure that representatives from Federal agencies, researchers, youth service providers, advocates, and young people develop, regularly update, and carry out a comprehensive, coordinated Federal agenda for AIDS research

on adolescents and young adults. This agenda should address the full range of research related to physical and social development, epidemiology, prevention, supportive care, and treatment, and it should direct the allocation of youth AIDS research funds within and among Federal agencies.

- In addition, the OAR should designate a senior staff member to help coordinate youth-focused AIDS research activities at NIH. OAR should use its budgetary authority to increase youth-focused research and to help implement the Federal research agenda on youth and HIV/AIDS.

The Federal government should ensure that appropriate resources are targeted to adolescent-specific AIDS research.

Implementing a youth-focused HIV research agenda will require a greatly expanded adolescent research infrastructure. It should, in part, build on existing efforts such as the Adolescent Medicine HIV/AIDS Research Network, and should be developed in collaboration with existing research groups and other stakeholders.

More research support is needed to study topics such as:

- those identified by the Working Group to Review the NIH Perinatal, Pediatric and Adolescent HIV Research Priorities;
- surveillance of HIV infection rates and risk behaviors among youth;
- determinants of risk behaviors among youth of color, sexual minority youth, and youth in high risk circumstances (e.g., homeless and runaway youth);
- multi-level prevention strategies (e.g., those that reach young people through school, parents and media);
- comprehensive prevention programs for high-risk youth;
- ways to tailor existing, evidence-based prevention approaches to address the needs of specific racial/ethnic and risk groups within the broader population of young people;
- service planning, coordination, and cost effectiveness;
- policies and other structures that enhance the delivery of evidence-based prevention programs for youth, and ways to encourage the creation of these structures;
- care-seeking behavior;
- the level of unmet need for services for high-risk youth;
- barriers to youth participation in clinical trials; and
- treatment regimens for adolescents that are easy to follow.

Federal agencies conducting HIV/AIDS-relevant clinical trials should take action consistent with Federal rules and regulations on research with minors to increase youth participation in the trials.

- NIH should promote increased research participation by HIV-infected young people in clinical trials. The recruitment, enrollment and retention of youth in the Adult AIDS Clinical Trials Group, Pediatric AIDS Clinical Trials Group, Community Programs for Clinical Research on AIDS, and the networks that evaluate vaccines and other preventive interventions should be improved. It may be necessary to pay special attention to increasing the participation of youth of color. All NIH AIDS research sites should document steps they are taking to enhance youth participation in studies and to gather the opinions and counsel of young people regarding recruitment issues.

- NIH, HRSA, and other Federal agencies should ensure that health care providers who work with HIV-positive youth are better educated about opportunities for participation in AIDS research. They should also be made aware of effective strategies for promoting youth participation in research.

Immediate and useful dissemination of research findings to local communities must be considered a key part of the research agenda.

As discussed under the Prevention Recommendations heading, Federal agencies that conduct research on HIV and AIDS should coordinate and expand their efforts to translate research results into practice. At the other end of the dissemination pipeline, schools and local service providers should settle for no less than evidence-based approaches. Active, two-way communication mechanisms must be developed more fully.

Conclusion

"...we're all worried about the choices our teenagers make... about how the best-laid plans for a bright future can be dashed with a single bad decision..."

Hillary Rodham Clinton,
White House Conference on Raising Responsible and Resourceful Youth

A safe passage into a productive, rewarding adulthood—this is our dream for our children. But, as William Butler Yeats said, "in dreams begins responsibility." Timid hopes for the best are not enough; families, businesses, communities, and government must join young people in realistic, vigorous action. Young people have a right to depend on us as adults. We must mobilize our nation's resources—resources that are unparalleled in American history—to protect and care for them.

We cannot slip into complacency about matters that should inspire us to act. We must not forget that the HIV and AIDS statistics assembled in this report are not really about numbers but about real young people who are just starting their lives.

And we cannot ignore our obligation to learn what we can about HIV prevention and care for young people, and to share these lessons abroad. Our advances in prevention science, medical science and practice can help turn the tide in the catastrophic global AIDS pandemic that has been declared a threat to our own national security.

Thanks to the very hard work of many people inside and outside of government, we have a growing arsenal of powerful weapons to use in the fight against HIV and AIDS. Youth culture and the virus itself are always changing, and our prevention and treatment approaches must keep pace.We must take full advantage of the sound strategies that we have at our disposal -- our children and our future are at stake.

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Attachment A

ACKNOWLEDGEMENTS:

In considering a course of action, ONAP sought advice from adult AIDS experts inside and outside of government, and from young people themselves. An advisory group was invited to provide guidance; we appreciate their contributions and have listed their names and affiliations at the time of initial group meetings below.

In addition, early in the process of writing this report, a focus group was conducted with HIV-positive young people to insure inclusion of their critically important point of view. For reasons of confidentiality, the young people who participated in the focus group are not listed here, but we are deeply grateful for their time and frankness.

Finally, we would like to acknowledge the helpful comments on a draft of this report that were provided by all the Federal agencies and offices the report mentions and from a number of others. ONAP particularly appreciates the support provided for development of the report from HRSA and the AIDS Alliance for Children, Youth & Families.

Rusty Bennett
HUD/ONAP
Washington, DC

Miguel Bustos
Office of Mrs. Gore
Washington, DC

Margaret Campbell
Wayne Wright Resource Center
JRI Health
Boston MA

Patricia Flynn, MD
Memphis HIV Family Partnership
Memphis, TN

Donna C. Futterman, MD
Montefiore Medical Center
Bronx, NY

Melvin Harrison
Navajo AIDS Network
Chinle, AZ

Khurram Hassan
Grady Pediatric-Adolescent
HIV/AIDS Program
Atlanta, GA

Joan Holloway
HRSA
Rockville, MD

Joyce Hunter
HIV Center for Clinical and
Behavior Studies
New York, NY

Loretta S. Jemmott, Ph.D.
University of Pennsylvania
Philadelphia, PA

Michele D. Kipke, Ph.D.
University of Southern Calif.
School of Medicine/
National Research Council
Washington, DC

Maria Lago
HRSA
Rockville, MD

Chad Martin
CDC
Atlanta, GA

Jaime Martinez, MD
Cook County Hospital
Chicago, IL

Cassandra McFerson
Metro Teen AIDS
Washington, DC

Hugh McGowan
Consultant to HRSA
Rockville, MD

M. Valerie Mills, Ph.D.
SAMHSA
Rockville, MD

Daniel C. Montoya
PACHA
Washington, DC

Matthew Murguia
OMH, DHHS
Rockville, MD

Angela Powell
HRSA
Rockville, MD

Ivonne Reyes
Teen Outreach Worker
University of Miami
Miami, FL

Audrey Smith Rogers,
PhD, MPH
NIH/NICHD
Bethesda, MD

Bret Rudy, MD
Children's Hospital
of Philadelphia
Philadelphia, PA

Jane Sanville
Office of National Drug
Control Policy
Washington, DC

Sean Sasser
PACHA/Health Initiatives
for Youth
San Francisco, CA

Margaret Scarlett, DDS
CDC/DHHS
Washington, DC

Richard Schulman
HRSA
Rockville, MD

Denise Stokes
PACHA
Stockbridge, GA

Todd Summers
ONAP
Washington, DC

Steven Tierney, EdD
Dimock Community
Health Center
Roxbury, MA

Alex T. Torrez
Bienestar Human Services
Los Angeles, CA

Ofelia Virtucio
Asian and Pacific Islander
Wellness Center
San Francisco, CA

Attachment B

Recommendations from *Youth & HIV/AIDS: An American Agenda* March, 1996

Action Requiring Cooperation From All Levels of Society

- Young people, parents, schools, and communities must be integral partners in developing, delivering, and evaluating HIV prevention approaches for adolescents.
- Innovative, creative prevention efforts aimed at young people must be encouraged, adequately funded, and evaluated, and—when found to be effective—broadly disseminated.
- Comprehensive HIV/AIDS education—as part of comprehensive health education—should be available to all young people in all fifty states and U.S. territories.
- Routine counseling and voluntary HIV testing should be made more accessible, developmentally appropriate, and affordable to young people.
- HIV-positive adolescents should be linked to a continuum of health care and support services that will extend their life span and provide them with the information and skills they need to reduce the likelihood of further transmission.
- Adolescent-specific biomedical and behavioral research should be increased to enhance our knowledge of the progression of HIV disease in adolescents and of the effectiveness of HIV prevention approaches and of HIV/AIDS treatments.

The Federal Role

- DHHS should create a forum of young people who are infected or affected by HIV as well as their parents, advocates, and providers to work with Federal officials to help identify and articulate the needs of adolescents in fashioning Federal responses to HIV and AIDS.
- HRSA should encourage the inclusion of young people and their advocates on AIDS care planning councils to help identify local needs and ways to target Federal funds to help meet the distinct developmental and comprehensive care needs of youth.
- CDC should encourage the inclusion of young people and their advocates in AIDS prevention planning councils to provide their unique perspective of the needs of youth in prevention efforts.
- The Federal government should continue to help the nation's schools and other youth serving agencies implement comprehensive programs to prevent the spread of HIV among young people.

- NIH and the Food and Drug Administration should continue to encourage the enrollment of adolescents in government and industry sponsored HIV/AIDS clinical trials.
- The Public Health Service should work with the researchers, clinicians, medical community, and patients to develop appropriate clinical practice guidelines for adolescents with HIV/AIDS.
- In releasing data from clinical trials, NIH and FDA should include specific data related to adolescents. In those cases where the number of adolescents participating in a trial is too small, anecdotal data should be released on a limited basis to allow clinicians an opportunity to begin building a base of information for their use in treatment.
- The Federal government should support expanded access to testing and counseling for young people. The CDC guidelines for testing and counseling should address the special needs of adolescents, such as developmental issues, processes for consent, confidentiality, and payment for services. As part of a grant application for counseling and testing funding, states should demonstrate the availability of testing and counseling services for young people.
- SAMHSA, CDC, and HRSA should collaborate on substance abuse treatment and prevention strategies affecting adolescents to ensure a coordinated effort.

Attachment C

GLOSSARY

ACTG	Adult AIDS Clinical Trial Group, sponsored by NIH.
AIDS	Acquired Immunodeficiency Syndrome
AMHARN	Adolescent Medicine HIV/AIDS Research Network, sponsored by NIH
ASPE	Assistant Secretary for Planning and Evaluation, DHHS.
CDC	Centers for Disease Control and Prevention
CPCRA	Community Programs for Clinical Research on AIDS, sponsored by NIH
CPG	HIV/AIDS Prevention Community Planning Group
Determinants	Factors that have been shown to predict a certain outcome, for example, a disease or risk behavior
DHHS	Department of Health and Human Services
EPDSDT	Early and Periodic Developmental Screening, Diagnosis, and Treatment
FDA	Food and Drug Administration
HIV	Human Immunodeficiency Virus - the virus that causes AIDS
HOPWA	Housing Opportunities for Persons with AIDS
HRSA	Health Resources and Services Administration
HUD	Housing and Urban Development
IDU	Injection drug user
IRB	Institutional review board

Job Corps	Federal job training program for economically disadvantaged youth
Microbicide	A topical agent that kills virus, but not necessarily sperm
NIH	National Institutes of Health
OMH	Office of Minority Health, DHHS
ONAP	White House Office on National AIDS Policy
PACTG	Pediatric and Adolescent Clinical Trials Group, sponsored by NIH
Regimen	A recommended schedule and dosage of a drug or therapeutic agent or activity
RWCA	Ryan White CARE (Comprehensive AIDS Resources Emergency) Act
SAMHSA	Substance Abuse and Mental Health Services Administration
SCHIP	State Children's Health Insurance Program
SPNS	Special Projects of National Significance
STD	Sexually transmitted disease
Surveillance	The regular monitoring of cases of a specific disease or health event
YRBS	Youth Risk Behavior Surveillance